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ABSTRACT

Practices in patient education for spinal cord injured persons in 10 hospital rehabilitation centers were examined. Surveys revealed that a majority of the centers conducted patient education (designed to provide facts about the injury as well as psychological support). Findings revealed a large number of staff involved, but a wide difference in the approaches and goals of patient education programs. Only three centers employed professionals with the primary designation of patient educator. There was also a lack of uniformity in materials, methods, and evaluation procedures. Further, the patient was not always encouraged to be an active member of the team, nor was either the rehabilitation counselor or special educator very involved in the rehabilitation center. (CL)

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# A Survey of the Practice of Patient Education with Spinal Cord Injured Patients in Rehabilitation Centers in the United States

(Paper to be presented at the April CEC Meeting.)

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## Introduction

For persons of all ages tramatic injury resulting in sudden and substantial physical loss is an overwhelming and catastrophic event. Paralysis, sensory, or mental impairment requires of an individual an enormous readjustment. Research has shown that the psychological state of the injured person is often a far more important factor in eventual good adjustment than the extent of the physical injury.

The spinal cord injured are of particular concern to professionals in education and rehabilitation for several reasons: First, these patients are likely to be adolescents or young men at the beginning of their lives and careers. (Their injuries have often been sustained in auto or sports accidents, and in violence or war.) Second, these patients must, after injury, rely on attaining a relatively high educational level in order to achieve vocational success. Thirdly, the protracted period of hospitalization and medical rehabilitation leaves a hiatus in the regular schooling, or reschooling of these patients. Lastly, although education is usually the salvation for these individuals in their greatly altered lives, they may feel so defeated and depressed that they may not only fail to prepare for a productive life, but may even neglect their physical needs, (which are considerable in the case of spinal cord injury) even to the point of death through self neglect, or suicide (Nyguist & Bors 1976). Studies indicate that those who are younger at the age of injury are inclined to be more debilitated and less independent than their older counterparts (Monks, 1976).

The processes of education and of rehabilitation and of psychological restitution itself are predicated on the patients' understanding and acceptance of their disability and their understanding of and cooperation in the treatment regimen. The development of these kinds of attitudes, knowledge, and skills are the province of patient education. Patient education is to be distinguished from simply training patients to cooperate, comply and accept what others tell them to do (American Hospital Association 1964, Redman, 1971, Skiff 1974, Wolle 1974).

While patient education has been increasingly accepted as a concept, a number of researchers have come to the conclusion that patients are still not well informed with regard to their illnesses (Shenkin & Warner, 1973; Young, 1979). Studies have shown that patients themselves are dissastisfied with their own limited knowledge about their disabilities. (Alt 1969; Linhan 1966; Mann 1973).

The Bill of Patients' Rights of the American Hospital Association specifically states that patients have the right to obtain information concerning their illness. Patient education has been accepted by many in the United States and Europe as an integral part of the rehabilitation process. As the American Medical Association stated in 1976,

> Information, motivation and participation in treatment by patients and their families, can aid the recovery of the patient and enhance the quality of his health. Patient education as an integral part of quality

health care, provides an avenue to such improved participation.

Therefore a number of professionals have encouraged efforts toward specific and formalized patient education programs for spinal cord injured patients (American Hospital Association, 1965; Skiff,1974; Shenkin,1975; Weinback & Dodge, 1974; Vaisrub, 1975).

The Survey (Bendel, 1980)

The objective of the present study was to investigate practices with regard to patient education for spinal cord injured patients in rehabilitation centers associated with hospitals in the United States. The investigators were able to identify virtually all such centers. By means of a broad survey some data on general practice in these centers were gathered. A detailed study was undertaken to investigate implementation of patient education in ten centers judged to be representative of all such rehabilitation centers.

Of the one hundred twenty-four hospitals serving spinal cord injured patients which were contacted, 77 responded (62% return rate), and 76 of these reported having a patient education program. In these hospitals the approximate number of spinal cord injured patients served by them at a given time was 1,274 and about one-fourth of the beds in the rehabilitation centers were occupied by spinal cord injured patients. The total number of staff members serving spinal cord injured patients was 4,483.

Ten of the rehabilitation centers representative in terms of type, size, and geographical distribution, were chosen to participate in a detailed

survey. A "fact sheet" was directed to the attending physician asking about specific characteristics of the rehabilitation center.

Findings from the survey:

The ten centers were surveyed to see if someone on the professional staff might be specifically designated as the patient educator. Several centers had educators who taught school subjects, but three centers specifically designated nurses and one psychologist as their patient educators. However, a majority of the centers did conduct formal patient education, and reported that much information was given on an informed basis. When asked what they emphasized in their programs, physicians, physical and occupational therapists and some nurses tended to emphasize the goal of patient education as physical restoration, while psychologists, social workers and some nurses tended to emphasize the goal of the patients' emotional restoration, as might be expected.

The areas of self care which were taught fell in the following categories: medication, diet control, bowel and bladder management, skin care, exercise techniques and sexual functioning. Teaching in these areas was generally shared by nurses, physicians, and physical therapists. However, teaching with regard to sexual function was the primary role of ten of the eleven psychologists who responded to the questionnaire, and many respondents felt that education with regard to sexual functioning was the most difficult for them to impart; albeit sexuality has been frequently demonstrated to be of primary importance to patients (Cole, 1975; Cole et.al., 1973; Eisenberg & Rustad, 1976).

The study showed that various staff members were quite autonomous in their dealing with various aspects of patient education. They relied on staffings, the medical charts, and informal communication to coordinate their efforts. Most reported that they had little communication with the patients family and they were not particularly inclined to include the patient in their planning. There was wide variability in practice concerning staff patient interaction. Personal interaction of any kind was discouraged as a matter of policy in one center, whereas 14% of all the staff reporting had some interaction with patients outside of working hours.

In two of the ten representative centers reporting, patient education was clearly initiated in the acute ward. The other centers wait until patients are transfered to the rehabilitation unit to begin this work.

Types of materials used for patient education for the spinal cord injured by various professionals within the different centers were researched.

The most frequently used materials for patient education are information leaflets, audio-visual teaching aids, library books and anatomical models. Closed circuit television, a telephone information line, and teaching machines are used by a small number of respondents from some of the larger centers.

In addition, field trips outside of the rehabilitation center are sponsored in one center, and role playing is used in another.

Special programs specifically designed for cord injured patients take place in three different centers. In one center, workshops for sexuality

and social skills are held. In another center, there is a special program to teach patients and their families about the program of the center. In still another, there is an optional group session including lectures by physicians or pharmacists, discussion about various aspects of the disability, and panel discussion with former patients. The family is invited to these sessions, in addition to an all day family group program.

Six centers also used some of the following techniques to evaluate the success of the program. A follow-up visit with the medical director; a pre- and post-rehabilitation questionnaire for the family; follow-up in the office or skin clinic; rehospitalization; out-patient recheck; periodic re-evaluation; reports of home health personnel, either written or by telephone.

Discussion

Since in the survey of 77 hospitals and rehabilitation centers, all but one center reported offering some patient education for the spinal cord patient, it can be assumed that this is considered an important component of the rehabilitation process. Further, the study revealed that there is a large population of cord injured patients served in medical rehabilitation centers at any given time, and a considerable number of professionals serving them. However, it was evident that the goals and practice of patient education differed widely among centers and between and among professions in ten centers.

Although the role of a patient educator has been identified in the literature, and as a specific professional role, only three centers employ

a professional with that primary designation; that is to instruct the patient in areas necessary for his mental and physical care as well as his vocational activities and to provide data about his psychological and physical progress for evaluation by the rehabilitation team. It was of great surprise that so few centers had a professional designated as a patient educator, who presumeably would coordinate and systematize a patient educator program.

The role of the patient educator does not seem to have been developed fully even in the three centers who have designated patient educators. The role description of the patient educator would suggest that he or she would be in a favorable position to coordinate the efforts of the rehabilitation team. There is a possibility that some centers might implement more effective patient education if there were such a coordinator. Since special programs are available in a variety of centers, it would seem that they could be used in more centers serving cord injured patients and might be highly effective.

With respect to educational materials and methods there was a lack of uniformity in practice. This might indicate that some centers might not be using the best combination of material and methods, at least for some indifiduals in the centers. However, some centers were using what appear to be very innovative materials and approaches to patient education.

Evaluation procedures differed widely in the centers, going from rather informal assessment of knowledge areas and observation of compliance to more structured techniques such as questionnaires, periodic interviews,

and rehospitalization. It might be very helpful for the various rehabilitation centers to share their many systems of evaluation in order to ascertain which are the most useful and effective. Without a systematic structure for the evaluation, certain areas might be over-emphasized and other overlooked. This is an area of great concern since the literature stresses the high rate of patients' non-compliance with the medical regime and maintenance of health.

Although it would seem important to have the patient as an active member of the team, the study seems to indicate this is not always encouraged. Since it is the patient himself who must eventually control his regime, it would seem important to involve the patients and the family or caretaker, since they can assist in the considerable adjustment after discharge from the hospital.

Of further note is the fact that neither rehabilitation counselors nor special educators seem to be much involved in the rehabilitation centers at all. In view of the fact that most of the patients can be expected to return to the world of school or the world of work at the end of their stay at the center, it appears that these professionals, valuable to this transition, would be excellent additions to the staff.

Summary and Conclusion

The intent of the survey described was to discover the extent to which patient education for spinal cord injured patients, widely advocated in the professional literature, is practiced in representative rehabilitation centers. A number of professionals seemed to be involved in systematic and

sometimes innovated practices. The investigators have concluded that educational management might be expanded and improved if communication and sharing within and between centers, and with patients themselves could be increased.

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